

# FAST FACTS ON: DEVELOPMENTAL DISABILITIES

2002

## AUTISM, ASPERGER'S and PDD

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*This scenario is a composite of various cases. The names are fictitious.*



Hannah's parents had been married eight years before she was born. They awaited her birth with much excitement and happiness. When she arrived, they were sure she was the most beautiful baby on earth. As Hannah grew, her parents deeply loved her, but were troubled by her passivity. She did not respond to their voices, and seemed indifferent to them. Although she liked to be held, she did not interact playfully. As atypical developmental patterns continued, they finally sought help and were told that Hannah had autism.

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## **Pervasive Developmental Disorders**

The term *autism* originated in the 1940's to describe atypical development characterized by problems with communication and social interaction. Autism is sometimes called a spectrum disorder because it ranges in degree from mild to more intense.

The American Psychiatric Association currently defines five disorders as being in the autism spectrum. The fourth edition of *Diagnostic and Statistical Manual of Mental Disorders* (DSM-IV) uses the term *Pervasive Developmental Disorders (PDD)* as an umbrella term for these five disorders.

### **Pervasive Developmental Disorders (PDD)**

- 1. Autistic Disorder**
- 2. Rett's Disorder**
- 3. Childhood Disintegrative Disorder**
- 4. Asperger's Disorder**
- 5. Pervasive Developmental Disorder/Not Otherwise Specified (PDD/NOS)**

All five are characterized by problems with social interaction, communication, lack of imaginative play, a limited range of interests, and repetitive activities. They differ by the child's degree of intelligence, impairment, and age that symptoms become noticeable.

There is some confusion about the term PDD. The DSMIV uses it to refer to the entire category of five disorders. It is not meant to be a diagnostic label, but is sometimes used as one. This usually happens for one of two reasons. 1).Some doctors use PDD as an abbreviation for PDD/NOS. 2).Others hesitate

labeling very young children with a specific disorder. These doctors label children as having PDD meaning that their behavior and characteristics indicate they have one of the disorders in the PDD spectrum.

Pervasive developmental disorders occur in all parts of the world and occur among people of every racial, ethnic, and social background. More boys than girls are diagnosed with all pervasive developmental disorders except Rett's disorder. Because of the importance of early intervention, some researchers believe very small children should be routinely screened for autism as they are for hearing and vision disorders (Sweeney & Neff, 2001).

New studies indicate higher rates of diagnosed pervasive developmental disorders than older studies. One current estimate of PDD is as high as 6 or 7 per 1,000 births (Bertrand et al., 2001). There is some indication that rates of diagnosis increase as service availability increases (Hillman, Kanafani, Takahashi, & Miles, 2000). Although more children are being diagnosed with pervasive developmental disorders, fewer receive the co-diagnosis of mental retardation (Hyman, Rodier, & Davidson, 2001). This may indicate that many higher functioning children with pervasive developmental disorder who might have remained undiagnosed in the past are now being diagnosed with PDD.

In the past, some people thought that emotional deprivation contributed to autism. It is now known that autism is a biological disorder, not an emotional disorder or mental illness. Poor parenting skills do not cause pervasive developmental disorders. The disorders result from the way that the nervous system develops.

The physical brain structure of people with autism differs from the brain structure of people without autism (Purcell, Zimmerman, Blue & Pevsner, 2001). Head circumference of children with autism and their relatives is often larger than typical. One study found that more 10% of people with autism and more than 15% of their first-degree relatives have head circumference large enough to be considered macrocephalic (Fidler, 2000). Although brain volume is usually in the normal range among newborns later diagnosed with autism, brain volume increases more rapidly than usual after birth (Courchesne et al., 2001). The brains of people with autism have extra cell minicolumns in the frontal and temporal lobes, but these cell minicolumns are unusually small, and are not arranged as compactly as minicolumns in the brains of people without autism. This finding is consistent with the theory that people with autism experience an overload of sensory information, and that their behavior is sometimes an attempt to combat this overload (Casanova, Buxhoeveden, Switala, and Roy, 2002).

Although genetic tests and brain scans are used for research purposes, they are not yet used to diagnose pervasive developmental disorders. At this time, autism and other pervasive developmental disorders are only diagnosed by observing behavior and symptoms. This is likely to change in the future as genetic and other medical tests are refined.

The unusual brain development in people with PDD probably results from a combination of genes that predispose a person to the disorder, as well as biological experiences that bring about expression of the disorder.

Following are some of the chromosomes and genes that have been linked with autism. It

is likely that more than one gene contribute to pervasive developmental disorders (Monaco & Bailey, 2001).

- ❖ Chromosome 7 -genes in the region of 7q31-33 (Wassink, 2001; Lauritsen & Ewald, 2001)
- ❖ Chromosome 15 – in a form of autism that includes low muscle tone and epilepsy (Wolpert et al., 2000).
- ❖ Chromosomes 2q and 16 (Monaco & Bailey, 2001)
- ❖ Chromosomes 5, X, and 19 (Liu et al., 2001).

Relatives of people diagnosed with autism often have behavior that sets them apart socially from other people, though they do not meet criteria for diagnosis with autism. People with autism often have close relatives that are undemonstrative, aloof, tactless, hypersensitive, anxious, shy, or eccentric (Murphy, et al., 2000). Several genes causing various combinations of traits may need to be inherited to have autism. Inheritance is sometimes more noticeable among families of people with Asperger's syndrome than among families of people with typical autism.

Environmental or biological factors may influence whether a genetic predisposition to autism results in a person actually having autism. Examples of these possible factors include the following:

- ❖ An immune response (Gupta, 2000).
- ❖ Measles/ mumps/ rubella vaccination associated with regressive autism (Wakefield et al., 1998). [This possibility is rejected by most in the medical community (Fombonne & Chakrabarti, 2001; Stratton, Gable, Shetty, & McCormick, 2001).

- ❖ A major life stress experienced during the 24<sup>th</sup> - 28<sup>th</sup> weeks of pregnancy (Beversdorf, 2001)
- ❖ Co-occurring digestive problems including the inability to properly break down the protein found in milk (Ross, 1999) and abnormalities in fatty acid metabolism (Richardson and Ross, 2000).

## Autism

Estimates vary as to how many children have autism. An extensive study done in Brick, New Jersey found that about four of every 1000 children are diagnosed with autism (Bertrand et al., 2001). Almost four times as many boys as girls receive this diagnosis. Children can be diagnosed as early as 18-24 months. Most are diagnosed by the time they are three or four years old.

Children who seem very different from each other may receive the same diagnosis. This is because they fall along a continuum from those children who are mildly affected to those severely affected. Only 3% of children diagnosed with autism injure themselves on purpose or act aggressively toward others.

Children diagnosed with autism have unusual behavior in each of four areas.

- ❖ Developmental delays in physical or social skills. Some skills may develop normally, while others develop slowly.
- ❖ Unusual response to stimuli. The child reacts unusually to things he/she sees, hears, tastes, smells, and/or touches.
- ❖ Language and speech are absent or delayed. (About half of the children diagnosed with autism do not use speech to communicate

socially, although they may repeat commercials or other things they hear.)

- ❖ Unusual responses to people, objects, and events.

Children with autism may avoid eye contact with other people. However, this symptom is not universal. Its absence does not rule out autism, nor does its presence confirm it. People with autism can be taught to look at others.

Some people with autism have only a mildly diminished ability to relate to others, while others are affected to a greater degree. They are less likely than other children to engage in pretend play.

Although children with autism sometimes point to an item if they want it, they are less likely to point to an item simply to show it to someone else. They are not as likely as other children to gaze in the same direction that an adult is looking.

Some children diagnosed with autism test as having normal intelligence, and some test in the gifted range. Mental retardation is commonly diagnosed in people with autism. However, increasing numbers of people are being diagnosed with autism without the co-diagnosis of mental retardation. The true intelligence of people with autism is sometimes underestimated, because most IQ tests rely on verbal skills, which are typically weak in people with autism. For this reason, IQ tests may not yield reliable scores, especially for people with extensive verbal impairment.

Children with autism who have normal or above normal intelligence are called *high functioning* by some professionals. Others use the term *high functioning* for children whose

social skills or communication skills are more like those of people without autism.

Over forty medical disorders occur more commonly in people with autism than they occur in the general population. Some of the medical disorders commonly associated with autism include epilepsy, hearing or vision impairment, and tuberous sclerosis. Sometimes a physical disorder like cerebral palsy or blindness is more obvious than autism, so it is diagnosed first. Approximately 10% of children who have cerebral palsy, and about 25% of children who are blind, also have autism. Anxiety – especially separation anxiety and obsessive-compulsive disorder, often occur among children with high-functioning autism (Gillott, Furniss, & Walter, 2001).

## **Rett's Disorder**

People with Rett's disorder (Rett's Syndrome) have a mutation on chromosome Xq28 of the MECP2 gene (Amir, 1999, and Wan, 1999.) Some people earlier diagnosed as having atypical Angelman or autism are now considered to have Rett's disorder (Watson et al., 2001). This disorder is diagnosed mostly among girls, but boys can also be affected (Dotti et al., 2002).

Children with Rett's disorder appear normal at birth. As months pass, head growth is a little slower than average. Early developmental stages are usually slightly delayed but within normal range. However, sometime between six and thirty months of age, children with Rett's disorder start to regress and lose communication, reasoning, and motor skills they had already developed. This is the point at which most parents realize that their child is not developing typically. Gradually,

children with Rett's disorder begin to move their hands in unusual ways and assume body positions that seem unnatural. Their breathing may become irregular. Epilepsy is common among children with Rett's disorder.

As children with Rett's disorder get older, they gradually recover some of the abilities they lost. Not all people with Rett's disorder are affected to the same degree. People mildly affected may have only slight learning disabilities, while those affected to a greater degree may have significant brain damage.

## **Childhood Disintegrative Disorder**

Childhood disintegrative disorder (CDD) is very rare. Children diagnosed with CDD seem to have typical development until they are at least two years old. Sometime between the ages of two and ten years old, they regress in several areas of functioning such as bladder and bowel control, the ability to move, or social and language skills.

## **Asperger's Disorder**

Asperger's disorder (AS) is also known as Asperger's syndrome, or simply Asperger's. It is on the mild and high functioning end of the PDD spectrum. A large number of people with Asperger's are not referred for diagnosis until adulthood, even though their childhood teachers recognized that they had problems with social interaction as children (Barnhill, 2001). It is believed that more people have Asperger's syndrome than have autism, but many people with Asperger's syndrome remain undiagnosed, or are misdiagnosed with Attention Deficit Hyperactivity Disorder (AD/HD) or emotional disturbance.

Some professionals believe Asperger's syndrome is the same as high functioning autism (HFA), which usually refers to autism without mental retardation. Others believe Asperger's syndrome is a completely different disorder from high functioning autism. The criteria distinguishing disorders are vague enough that the same children may be diagnosed as having Asperger's syndrome, high functioning autism, or PDD/NOS, depending on the person evaluating them.

Children with Asperger's syndrome do not have the same degree of verbal impairment that children with autism do. Their vocabulary and grammar is usually normal and sometimes superior. However, they have subtle problems with social language. They commonly misinterpret the meaning of what people say. They understand the words, but often have trouble discerning whether the statement was made seriously, jokingly, or sarcastically. They tend to use language to communicate specific information or to obtain something rather than to engage in social talk. They often misread facial expressions and misinterpret people's motives.

Children with Asperger's often have a narrow range of interests, with an overriding interest in one particular topic. They may memorize large amounts of detailed information about things they find interesting. They often possess keen memories and good visual discrimination, but are less adept at comprehension (because they take things too literally) and problem solving.

Many children with Asperger's have unusual sensory responses. They may find bright light or flickering lights intolerable, or they may insist on and appreciate bright light. They may find noises intolerable that are at a pitch so high that most people do not hear them.

They may be supersensitive to touch and resist sudden physical contact, even by people they like.

People with Asperger's syndrome may find it difficult to participate in the feelings and interests of other people. They often wish to make friends but lack the social skills necessary to do so. They have trouble learning what is sometimes called "the hidden curriculum" – customs that most people pick up automatically and unconsciously without being explicitly taught. They may feel alienated from other people and overwhelmed by the everyday demands of interacting with others because they do not understand the subtle and unspoken social rules that most people take for granted.

People with Asperger's syndrome have average, above average and sometimes very high IQs. Most children with Asperger's syndrome are educated in regular school classrooms. Many go to college and graduate school.

Many people with Asperger's syndrome have poor motor-visual skills that prevent them from excelling at manual labor. However, their intense interests can sometimes be developed into productive careers.

Adults with Asperger's sometimes struggle with the social competence demands of the workplace. Lack of social intuition and adaptation may result in job loss from time to time. Systematic direct instruction in social skills can enable people with Asperger's to function more effectively at school or in job situations (Myles & Simpson, 2001).

## **PDD/NOS**

PDD/NOS stands for pervasive developmental disorder / not otherwise specified. About three or four times as many children are diagnosed with PDD/NOS as are diagnosed with autism. Children are usually diagnosed with PDD/NOS for one of the following reasons.

- ❖ They have some but not all the symptoms associated with other types of PDD, or
- ❖ They meet the criteria, but lack the degree of impairment described for other types of PDD.

Children diagnosed with PDD/NOS have different types and intensities of unusual behavior. Some have behavior so mildly atypical that most school and work acquaintances do not notice it. Others have difficulty in almost every area of life.

Children diagnosed with PDD/NOS have many of the same characteristics as those diagnosed with autism. Babies often avoid eye contact. Most do not stretch their arms to be picked up. They may be indifferent to affection and seem to not bond. They seldom nod their heads *yes*, or shake them *no*.

As they grow, children may develop attachment to their parents, but they still have problems with peer relationships. They may wish for friends, but find it difficult to respond to other people's interests and emotions in socially appropriate ways.

Children diagnosed with PDD/NOS seldom gesture, even if they understand the gestures of others. They may show fear, anger and joy, but usually only in extremes. Some children giggle or scream for no obvious reason. They rarely use facial expressions showing subtle emotions.

Children diagnosed with PDD/NOS usually resist change in their routines. They sometimes have ritualistic or compulsive behaviors like wanting to eat only one particular food, repeatedly moving their hands in a certain way, or memorizing lists or tables that seem pointless to commit to memory. Some children with PDD/NOS become intensely attached to age-inappropriate objects.

Speech impairment ranges from very mild to severe. Sometimes speech seems normal, as is seen in Asperger's syndrome. Other times, speech is so affected that the only speech acquired is echolalia (the seemingly meaningless repetition of words or phrases.) Pronunciation problems are common, and sometimes speech has a flat monotonous tone.

## **Supports for Pervasive Developmental Disorders**

The pervasive developmental disorder spectrum encompasses a broad range of people. Even people with the same assessment are very different from each other and need different supports. Alternative supports and approaches abound. Some (including some of the interventions mentioned below) are controversial and/or have not been scientifically validated. Parents are urged to keep informed about new treatments, but to consider them carefully before agreeing to implement them.

**Anti-fungal Therapy:** Anti-fungal medication has sometimes been associated with an improvement in autistic symptoms (Page, 2000).

**Anti-yeast Therapy:** If children have a yeast overgrowth from too many antibiotics, anti-yeast medication may decrease negative

behavior. Research on this treatment is not yet conclusive.

**Applied Behavioral Analysis (ABA):** Applied behavioral analysis involves analyzing behavior and setting up a plan to change it through reinforcement. Behavior is “shaped” by reinforcing responses to stimuli. Some people use the phrase *applied behavior analysis* narrowly to refer to only one particular method of doing this - discrete trial training as described by Lovaas and his students. Others use the phrase *applied behavior analysis* to refer to a variety of structured, consistent and effective behavior interventions (Heflin & Alberto, 2001; Simpson, R.L., 2001). For information about the ABA advocated by Lovaas and followers, please see the description of *Discrete Trial Training*.

**Auditory Integration Therapy (AIT):** The premise of this therapy is that some of the characteristics of autism result from hypersensitivity at certain sound frequencies, making common sounds painful. This therapy involves a machine that sends random high and low sounds through a headphone to the child. There are currently two types of machines now in use: the Audiokinotron, and the BGC. According to anecdotal reports, Auditory Integration Therapy helps communication and social behavior. However, the research on this method is still limited. Dr. Bernard Rimland, Director of the Autism Research Institute (619) 281-7165 may be contacted for a list of AIT practitioners.

**Casein Free and/or Gluten Free Diet:** This diet has been shown to effectively reduce symptoms of autism among people with abnormal excretion of peptide (Page, 2001 citing Knivsberg et al, 1990 and Reichelt, Knivsberg, Nodland & Lind, 1994). It has not yet been proven useful for all people with

autism. Casein is found in milk. Gluten is found in wheat and in some other grains. A casein free and gluten free diet involves the elimination of all dairy products, as well as the elimination of most bread and cereal products. As the diet has become more common, substitute products can be found in health food stores and in some grocery stores, as well. Dr. Lisa Lewis, university professor and parent of a child with autism, has been experimenting with this diet and has a web site with information on it. She requests input from other parents of children with autism who use a casein free and/or gluten free diet:

Dr. Lisa Lewis  
156 E. Delaware Ave.  
Pennington, NJ 08534

<http://www.princeton.edu/~serge/ll/gfpak.html>  
[lisas156@aol.com](mailto:lisas156@aol.com)

**Discrete Trial Training:** (Also known as Intensive Behavior Intervention.) This is a form of applied behavior analysis developed by Lovaas. Training is given one on one in a setting free from unnecessary distractions. A cue is presented along with a prompt to help the child respond appropriately to the cue. A correct response receives positive reinforcement. After a short pause of 1-5 seconds, the cue is presented again. Children may spend 2-5 minutes in sessions being presented with cues at the rate of about 12 or more per minute. After each 2-5 minute session, they receive a one or two minute break before beginning again. At the end of every hour they may receive a 10-15 minute break. There is usually a one or two hour break during the middle of the day. Treatment may last 6-8 hours per day, 6 days a week (Smith, T., 2001).

**Facilitated Communication:** A facilitator helps an individual communicate in alternative ways. One method consists of the facilitator



resting his/her hand on the hand of the person with autism who then writes. A facilitator also may help spell words on a computer keyboard or other letter display.

**Immune System Therapy:** There is increasing evidence that people with autism have immune system abnormalities. Intravenous immunoglobulin therapy is the treatment commonly recommended by proponents of immune system therapy. Although many professionals question the value of this treatment, ongoing research is being conducted in this area.

**Inclusion:** Following are supports that have been documented as being useful in including children with pervasive developmental disorders in general school classrooms (Harrower, J.K. & Dunlap, G., 2001).

- ❖ Circle of Friends: A core group of peers who have agreed to give social support. There should be as much continuity as possible in the circle of friends over the years.
- ❖ Delayed and unpredictable contingencies: By making outcomes and rewards less predictable, behavior changes may become generalized and may be more likely to persist.
- ❖ Peer mediated interventions: These are sometimes useful and consist of peer academic tutoring, peer social supports, and cooperative learning.
- ❖ Picture schedules: These increase predictability and help students change from one activity to another.
- ❖ Prepractice (also known as priming): Information or activities are previewed with a child before that child participates in the activity in the general setting.
- ❖ Prompts: Prompts can be given by teachers, peers, or by mechanical devices.

- ❖ Social Stories: Social stories, as developed by Carol Gray, are individualized written prompts that teach appropriate behavior in social situations. Stories may remind someone to substitute acceptable alternatives for challenging behavior, they may instruct how to do an activity, or they may remind a person how to handle emotions like anger or frustration.
- ❖ Teaching self management strategies: Students are taught to recognize the difference between appropriate and inappropriate behavior, and are taught to monitor and reinforce their own behavior when it meets specified standards.

**Individual Educational Plans and Individualized Family Service Plans:** If children are school age and need special educational services, the school is required to develop an Individualized Educational Plan (IEP) with parent involvement. Children younger than three years old who need interventions have Individualized Family Service Plans (IFSP). [See *Fast Facts on Developmental Disabilities: Navigating the System*; and *Fast Facts on Disabilities: Individual Educational Plan*, available from the DDRC Resource Center by calling (800) 444-0821, or online [www.moddrc.com](http://www.moddrc.com) ]

**Massage Therapy:** A study done on twenty children with autism who ranged from three to six years old indicated that children who received 15 minutes of massage prior to bed each night had less hyperactivity and off-task behavior, less stereotypical behavior, and fewer sleep problems (Escalona et al., 2001).

**Medication:** At this time, the Federal Food and Drug Administration has not approved any medicine as a specific treatment for PDD.

- ❖ Whole blood serotonin is elevated in about 30% of patients. In relation to this,

serotonin reuptake blockers and also medicine that blocks both dopamine and serotonin may benefit some people with PDD (Buitelaar, 2000).

- ❖ Medicine is sometimes administered to treat symptoms associated with PDD. For example, if children with autism also show signs of hyperactivity, they are sometimes given medications such as Ritalin. If they are anxious or depressed, they may be given medicines such as fluoxetine or clomipramine to decrease levels of anxiety, depression, repetitive thoughts and behavior, or aggression (McGough, et al., 2000). Halioperidol, an antipsychotic is sometimes effective, but it has a risk of serious side effects in children (Campbell, Armenteros, & Malone, 1997). Anticonvulsants or steroids are sometimes given to people with autism who also have seizures (Tuchman, R., 2000).
- ❖ Secretin. Two rigorous scientific studies (one involving twenty children, and one involving 17 children) did not find secretin to have an effect on language in contrast with a previous study done on only three children (Lightdale, 2001; Chez, M.G., 2000).

**Metabolic Disorder Interventions:** A small minority of people with pervasive developmental disorders have been diagnosed with enzyme defects that interfere with metabolism. When the specific enzyme is correctly identified and compensated for with vitamins/minerals, special diets, or other chemical interventions, autistic symptoms sometimes improve. Sometimes an unusual concentration of metabolites in people with autism may be due to microbial origin rather than due to an enzyme defect (Page, 2000).

**Music Therapy:** Music therapy is sometimes used because it is nonverbal and non

threatening. Trained music therapists use music to help change social behavior and to encourage cognitive and motor skills.

**Occupational Therapy:** Occupational therapists help improve fine motor skills like holding a pencil and tying shoelaces. They also help with sensory integration (see below).

**Picture Exchange Communication System (PECS):** An eight step approach to helping a nonverbal child communicate using pictures.

**Positive Behavior Supports:** Positive behavior supports help children substitute more pleasing behavior for challenging behavior. Emphasis is placed on identifying the specific events or circumstances in the environment that trigger challenging behavior, and then working to change or eliminate them. Several weeks are required for each new behavior to be integrated into the child's life.

1. Undesirable behavior is analyzed to find what function it has.
2. Environmental triggers for the challenging behavior are identified and eliminated or modified.
3. Other behavior is identified or taught that is more effective and fulfilling than the challenging behavior.
4. Challenging behaviors are replaced one by one, not all at once.

**Psychotherapy:** Psychotherapy may help some children diagnosed with autism or PDD/NOS to cope with the difficulties they face socially.

**Sensory Integration Therapy:** A person trained in sensory integration helps an individual learn appropriate responses to a wide range of sensory stimulation. This is one of the main treatments used by Occupational

Therapists. The treatment is very individualized. Children often enjoy it because it seems like playing to them. Treatment may last from six months to two years. [See *Fast Facts on Developmental Disabilities: Sensory Integration*, available from the DDRC Resource Center by calling (800) 444-0821, or online [www.moddrc.com](http://www.moddrc.com) ]

**Social Skills Instruction:** Some social skills can be directly taught by adults. Examples include facial expressions, showing sympathy, showing appreciation, asking questions, and sharing toys. In recent years, there has been increased emphasis on peer mediated approaches in which typically developing peers interact with a child with autism. These interventions are often most successful if the typically developing children have been instructed in ways to initiate interaction with the child with autism. Sometimes play is mediated or structured by adults in such a way as to involve the child with autism and provide social learning experiences for him or her. Many studies in this area have involved only two or three people with autism. More large-scale scientifically designed studies need to be done to find best practices in this area.

**Speech Therapy:** Speech therapists can help identify the ways a child communicates with words, gestures, and symbols. They also work with speech articulation, loudness, and pitch.

**Treatment and Education of Autistic and related Communication-handicapped Children (TEACCH):** This method of intervention emphasizes visual learning, individualized curriculum, structure and predictability, and promotes supports rather than focussing on behavior. It is compatible with other types of therapy. This therapy is low stress on parents, resulting in fewer out of home

placements than many other methods (Autism Society of America, [www.autism-society.org](http://www.autism-society.org)).

**Vitamin/Mineral Therapy:** Studies have shown the following supplements to be useful for some people with pervasive developmental disorders (Page, 2000):

1. pyridoxine and magnesium given together;
2. calcium;
3. folic acid for people who are co-diagnosed with autism and fragile X syndrome: (too large a dose of folic acid increases symptoms).

Children with pervasive developmental disorders are usually identified initially because of developmental delays. However, some children with PDD have precocious and “gifted” development in specific areas.

Children with pervasive developmental disorders tend to be better at visual discrimination and visual search tasks than typically developing children (O’Riordan & Plaisted, 2001). Many who are high functioning have photographic or near-photographic memories. Some also memorize information easily when they hear it. They are often known for the vast amount of information stored in their memories.

Some children with high functioning autism, Asperger’s or PDD/NOS are fascinated with letters at an early age and learn to read almost effortlessly before they are in school. The term *hyperlexic* is used to describe these children who learn to read easily and early, yet manifest delays in abstract thinking and comprehension in some areas.

Children with PDD are individuals, and their needs for support vary. However, it is

generally acknowledged that early and intensive intervention is helpful. The specific programs that are most useful depend upon the particular needs of the children and their families.

Pervasive developmental disorders are life-long. There are no “cures” although behavior can be changed in ways that lead to more rewarding interactions with other people. Children with pervasive developmental disorders can establish close relationships with others, but they will always be challenged by some of their differences. At this time, many people with autism (as well as many with other developmental disabilities) are unemployed or underemployed. People of high intelligence with autism may find it easier to graduate from college than to obtain and retain a job that suits their skills. Job interviews and corporate social expectations are often impediments to their career success (Romoser, 2000).

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## Support Groups

### **Autism Society of America**

Western Missouri Chapter  
Jackson County Board of Services  
8508 Hillcrest Road, Kansas City, MO  
(816) 353-7560

### **Asperger Parent Support Group South Kansas City Parent Support**

127<sup>th</sup> and Quivira  
Overland Park, Kansas  
<http://www.aspergerparent.org>  
Email: [heinrichs@peoplepc.com](mailto:heinrichs@peoplepc.com)

### **Northland Parent Support Group**

Liberty, Missouri  
Press & Gena Barnhill,  
Email: [genabarnhill@hotmail.com](mailto:genabarnhill@hotmail.com)

### **Judevine Support Groups**

- ❖ Rural Central Missouri  
Judevine Autism Outreach Program  
(800) 675-4241  
Email: [bohanian@worldnet.att.net](mailto:bohanian@worldnet.att.net)
- ❖ St. Louis  
Judevine Center for Autism  
Support groups: (314) 849-4440  
Siblings: (314) 432-6200 Ext. 528  
Young adults with Asperger's: (314) 432-6200  
Email: [judevine@judevine.org](mailto:judevine@judevine.org)

### **Older Teens and Young Adults Group**

Shawnee, Kansas  
AARC at 913-588-5988, or  
Mr. and Mrs. Petro at 913-631-4894

## Resources:

### **Autism Asperger Resource Center**

University of Kansas Medical Center

Kansas City, Kansas

(913) 588-5988

<http://www.autismasperger.org/index.html>

Email: [aarc@kumc.edu](mailto:aarc@kumc.edu)

### **Autism Project:**

University of Missouri - Columbia

Assessment and Services

(573) 882-5092; (573) 884-2131

Matt Stoelb: [mps8cb@mizzou.edu](mailto:mps8cb@mizzou.edu)

Heather Bate: [BateH@missouri.edu](mailto:BateH@missouri.edu)

### **Autism Research Institute**

Promotes the views of Dr. Bernard Rimland

San Diego, CA

(619) 281-7165

<http://www.autism.com/ari/>

### **Autism Society of America**

Bethesda, Maryland

(800) 3 AUTISM; (301) 657-0881

<http://www.autism-society.org/>

Autism Info: [info@autism-society.org](mailto:info@autism-society.org)

Chapter Info [membership@autism-society.org](mailto:membership@autism-society.org)

### **Autism Society of Johnson County, Kansas**

Contact Monica Walker at (913) 631-9970

Email: [monica@buttonkingdom.com](mailto:monica@buttonkingdom.com)

[www.asjck.org](http://www.asjck.org)

### **Autism Society of Kansas**

Wichita, KS

Reach us through the ARC: (316) 943-1191

<http://www.ask.hostrack.net/>

Email: [askkansas@worldnet.att.net](mailto:askkansas@worldnet.att.net)

### **Center for Autistic Disorders**

Children's Hospital, Columbia, Missouri

Diagnostic evaluation and medical therapy

(573) 882-6991

<http://www.genetics.missouri.edu/Autismhome.htm>

### **Center for Innovations in Special Education (CISE)**

University of Missouri-Columbia

(573) 884-7275

(800) 976-2473 (MO only)

TDD: (800) 735-2966

<http://tiger.coe.missouri.edu/~mocise>

E-mail: [mocise@missouri.edu](mailto:mocise@missouri.edu)

### **Center for the Study of Autism**

Salem, Oregon

Voice/fax: (503) 692-3104

<http://www.autism.org/>

### **Central Missouri Autism Project**

(Judevine Autism Outreach Program serving people in rural central Missouri)

Columbia, Missouri

(573) 874-3777

(800) 675-4241

<http://www.coin.org/community/soc-services/judevine.html>

Email: [bohanian@worldnet.att.net](mailto:bohanian@worldnet.att.net)

### **Center for Innovations in Education (CISE)**

800-976-CISE (Missouri only)

(573) 884-7275

Columbia, MO

<http://www.coe.missouri.edu/~mocise>

### **The Cure Autism Now Foundation (CAN)**

Los Angeles, CA 90036

(323) 549-0500

<http://www.canfoundation.org/>

Email: [CAN@primenet.com](mailto:CAN@primenet.com)

### **Department of Elementary and Secondary Education, State of Missouri (DESE)**

Jefferson City, MO

573-751-4212

<http://www.dese.state.mo.us/>

### **Developmental Disabilities Resource Center (MODDRC)**

Kansas City, Missouri

(800) 444-0821; (816) 235-1763

[www.moddrc.com](http://www.moddrc.com)

The MODDRC has a collection of books, manuals, articles, videos and audio-tapes on autism, and other disabilities and disability related topics. Some articles (including the following) are available online.

- *Fast Facts on Developmental Disabilities: Navigating the System When Your Child Has Special Needs*
- *Fast Facts on Developmental Disabilities: Individual Education Plan*
- *Fast Facts on Developmental Disabilities: Positive Behavior Supports*

### **East Missouri Autism Project**

St. Louis, Missouri

(314) 877-1201

### **Gateway Autism Organization (GAO)**

Marla Taggart, President

St. Louis, Missouri

Helps families network, and problem solve

(314) 640-5227 or (314) 845-2711

Email: [Mktaggart@aol.com](mailto:Mktaggart@aol.com)

### **Judevine Autism Outreach Program to People in Rural Central Missouri**

(800) 675-4241; Email: [bohanian@worldnet.att.net](mailto:bohanian@worldnet.att.net)

<http://www.coin.org/community/soc-services/judevine.html>

### **Judevine Center for Autism (St. Louis)**

(314) 849-4440

<http://www.judevine.org/>

Email: [judevine@judevine.org](mailto:judevine@judevine.org)

### **MAAP Services Inc.**

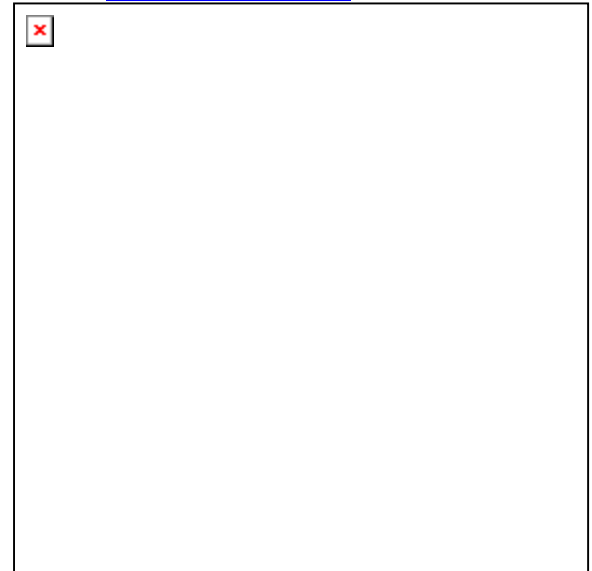
Asperger's, PDDNOS, and High functioning autism

MAAP Newsletter

(219) 662-1311

<http://www.maapservices.org/index.html>

Email: [chart@netnitco.net](mailto:chart@netnitco.net)



### **Missouri Autism Program**

Missouri Department of Mental Health  
Jefferson City, Missouri  
(573) 751-4054  
Email: [dmhmail@mail.state.mo.us](mailto:dmhmail@mail.state.mo.us)  
<http://www.modmh.state.mo.us/mrdd/>

### **Missouri Families for Effective Autism Treatment (MOFEAT)**

Missouri chapter of a national effort to promote the discrete trial training introduced by Lovaas.  
contact: Anna Leitch  
(573) 447-3328  
<http://www.mo-feat.org/>

### **Missouri Protection and Advocacy**

TDD: (800) 735-2966  
Jefferson City: (800) 392-8667  
St Louis: (800) 233-3958  
Kansas City: (800) 233-3959  
Cape Girardeau: (800) 356-3163  
De Soto: (877) 321-4419  
Springfield: (888) 632-9551  
<http://members.sockets.net/~mopasjc/MOP&A.htm>

### **Missouri's Coordinator for Autism Services**

Jefferson City, Missouri  
(573) 751-4054  
(573) 751-8217 (TT)

### **Missouri Parents Act**

Advocacy group for parents of children with disabilities  
(800) 743-7634  
<http://www.ptimpact.com/>

### **The National Alliance for Autism Research (NAAR)**

National alliance of families and researchers to fund autism research.

Princeton, NJ  
Voice/fax: (908) 359-9957  
<http://www.naar.org/>  
Email: [naar@naar.org](mailto:naar@naar.org)

### **National Information Center for Children and Youth with Disabilities (NICHCY)**

(800) 695-0285  
Email: [nichcy@aed.org](mailto:nichcy@aed.org)  
<http://www.nichcy.org>

### **Northwest Missouri Autism Project**

Kansas City, Missouri  
(816) 889-3449

### **Project Access**

Cooperative Project of the Missouri Department of Elementary and Secondary Education and Southwest Missouri State University  
Provides autism consultants statewide to school districts: professional development and library resources  
Toll free (866) 481-3841; (417) 836-6755  
Email: [ProjectACCESS@smsu.edu](mailto:ProjectACCESS@smsu.edu)  
<http://www.smsu.edu/Access/proaccess.html>

### **Resource Guide: Possible intervention techniques for persons with autism spectrum disorders.**

A guide to information on the internet.  
<http://star.nm.org/discuss/resources/>

### **Southeast Missouri Autism Project**

Cape Girardeau, Missouri  
Lacey Warren, Project Director  
(573) 339-9300  
(800) 583-3846  
Email: [semojca@mvp.net](mailto:semojca@mvp.net)

### **Southwest Missouri Autism Project**

Springfield, Missouri

Judevine Outreach Services  
Kerry Duncan, Project Director  
(417) 890-1399

<http://www.judevineswmo.org/index.html>  
Email: [kerri@judevineswmo.org](mailto:kerri@judevineswmo.org)



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